

SOCIAL WORK BEST PRACTICES FOR CAREGIVER SUPPORT

CMSC San Diego
May 31, 2012



Faculty

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CMSC San Diego
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CMSC San Diego, May 31, 2012

Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Describe characteristics (epidemiology) of the MS Informal Caregiver.
2. Describe commonly used Caregiver Assessment tools used to determine caregiver stress and burden to determine intervention strategies.
3. Describe several Caregiver Support Models and Interventions used in practice to support the MS Informal Caregiver.



Agenda

1. Epidemiology, Assessment & Models of Treatment for the Informal Caregiver

❖ Alicia Sloan & Jamie Wazenkewitz

2. Implementation into Social Work Practice:

❖ Allison Fine & Megan McDaniel

3. Group Discussion of Case Studies & Current Practice

❖ Lisa Webb

Epidemiology, Assessment & Models of Treatment for the Informal Caregiver

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MS Center of Excellence–West
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“Informal Caregivers” Defined

- ▶ “An individual who cares for a friend or family member through helping the care recipient with activities of daily living or instrumental activities of daily living.” (Multiple Sclerosis Caregivers Report, 2012)
- ▶ “An unpaid person who helps with the physical care or coping with the disease.” (Hileman, et al., 1992)
- ▶ “With MS, it is often a family member, a partner, parent or adult child.” (CMSC website: www.ms-care.org/cm-sc/News/Web-Sights-Caregivers-Stress-2.html)
- ▶ Informal caregivers are the primary resource allowing people with MS to remain in their homes. (Dunn, 2011)
- ▶ CG = Informal Caregiver



The Caregiver isn't my client.

Yes or No?



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Sloan, CMSC San Diego, May 31, 2012

Slide 7

Myth: The Caregiver isn't my client.

Reality

- ☑ Multiple Sclerosis is a “family affair.” The best care you can give to the Caregiver means the best care you can give to your client with MS.
- ☑ Most Caregivers will appreciate the time you take to listen to their own needs and have their own situation taken seriously.

If I help the Caregiver, I won't have time to complete my other responsibilities with my MS client.

Yes or No?



Adapted from Frederickson & Schug presentation, Seattle VA Puget Sound, 2011

Sloan, CMSC San Diego, May 31, 2012

Slide 9

Myth: I won't have time to help the Caregiver.

Reality:



Caregivers may provide significant insights into the client's situation and identify important issues that are overlooked.

History of MS Caregiving Research

1980: General Caregiver Burden in chronic disease research began.

1997: First Quality of Life Study of people w/MS and their Caregivers – Aronson

- CG has a poorer QOL if...
 - ✓ A spouse.
 - ✓ Has longer duration of caregiving.
 - ✓ Moderate or worse MS symptoms in care recipient.
 - ✓ Care recipient has unstable MS disease course.

History of MS Caregiving Research, con.

Dunn Lit Review (2011): Good review of MS Caregiver Research over 20 years.

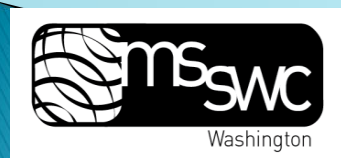
- Reduces cost of outside paid caregiving.
- ‘Hidden patient’ – physical, emotional, psychological, social and economic burdens. (Buhse Study, 2008)
- 75% live with care recipient and 42% sole CG.
- Average duration = 9 years.
- Loss of mobility = greater burden for CG.
- May not be prepared for physical tasks. Recommends CG training.
- Health problems of MS patients mirrored in their CGs.
- ▶ CG should be targeted for focused therapeutic strategies. (Pozzilli study 2004)

History of MS Caregiving Research, con.

- **Respite/Palliative Care:** Reduces CG burden.
(Edmonds, 2010)
- **Family Systems/Young CGs:** Young caregivers affected positively & negatively by parents w/MS.
(Pakenham, 2007, 2012)

Latest on MS & CG:

- Multiple Sclerosis Caregivers Report, 2012.
 - ✓ Study by the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research.



Who are MS Caregivers?

From 421 MS Caregiver Respondents:

- ▶ Male 40%
- ▶ Female 60%
- ▶ Ave. Age 46 (range 25–86%)
- ▶ 72% Married or living with a partner
- ▶ 38% have Children under age 18 in the household
- ▶ 2/3 have College or Graduate degrees
- ▶ 70% Household Incomes were >\$50,000/year
- ▶ Median Income for all respondents \$79,000
- ▶ 58% Employed Full-Time

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Washington

Road to Caregiving

- ▶ 30% spouse/partner
- ▶ 26% son/daughter
- ▶ 10% sibling
- ▶ 7% friend or neighbor
- ▶ 5% parent
- ▶ 15% other relative (aunt/uncle, grandchild, cousin, in-law)
- ▶ 3% other



Multiple Sclerosis Caregivers Report 2012

from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Choice in Providing Care

- ▶ Almost half (48%) of respondents felt they did not have a choice in taking responsibility for caring for the person with MS.

Multiple Sclerosis Caregivers Report 2012

from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Time Spent Caregiving

- ▶ 24 hrs/wk average spent caregiving
- ▶ 13% spend > 40 hours/week caregiving
- ▶ Activities of Daily Living (ADLs) involved in caregiving: bathing, dressing, feeding, toileting, etc.
- ▶ Instrumental Activities of Daily Living (IADLs): shopping, housekeeping, transporting to doctor, cooking, handling finances, etc.

Multiple Sclerosis Caregivers Report 2012

from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



External help for caregivers

- ▶ 27% of CGs are the only CG, but those who have supplemental paid in-home care support spend the same amount of time providing care as those who do not.

Multiple Sclerosis Caregivers Report 2012

from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



MS Caregiver Burden



MS symptoms that increase burden on CGs

- Difficulty walking
- Cognitive Impairments
- Depression/anxiety
- Frequency of bladder dysfunction
- Instability of symptoms

CG Health Problems

- Tiredness
- Depression
- Back pain
- Insomnia
- Shortness of breath

✓ Notice how many mirror the care recipient's MS symptoms?

Dunn (2011), MS Caregivers Report (2012)

MS Caregiver Burden, con.

- ▶ Most commonly reported emotional responses felt by caregivers in response to initial MS diagnosis: Compassion, followed closely by fear and anxiety.
- ▶ Negative impacts of caregiving reported:
 - overall financial situation (43%)
 - ability to participate in hobbies (39%)
 - mental health (38%)
- ▶ 1 / 3 suffer depression because of providing care.
- ▶ 1 / 2 are physically exhausted.
- ▶ Nearly 1 / 3 have experienced physical injury as a result of caregiving.
- ▶ 22% have lost a job due to caregiving.
- ▶ 17% report not being able to hold down a job due to caregiving.

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Stages of Readiness of Support

Identified Phases in Caregiver's decision to seek and accept support:

1. Rejecting support
2. Resisting support
3. Seeking support
4. Accepting support



Source: McKeown, 2004.

Male MS Caregiver Burden

Buchanan Study

- National survey: Focused on MS male caregivers. (Buchanan, et al. 2011)

Results

- Greater burden assoc. greater hours per week providing assistance.
- Strong assoc. between perception of burden & mental health status of male CG



Positive Impacts on Caregivers

- Positive impact on relationships with care recipient, children and other family members (74%)
- Health/in better shape (36%)
- Emotionally rewarding (25%)
- Better outlook on life (22%)
- Save more money (21%)
- Doing new hobbies with care recipient (19%)

Multiple Sclerosis Caregivers Report 2012

from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research

- Health of person w/MS associated w/caregiver perceptions that providing assistance strengthened caregiver/care recipient relationship. Nat'l NARCOMS survey: 530 CGs (Buchanan & Huang, 2011)

Impacts on Relationships: Caregiver Challenges

Relationship/Family

- ▶ Frustration with care recipient (42%)
- ▶ Increased arguing with care recipient (14%)
- ▶ Doesn't have enough time to spend with other family members (27%)
- ▶ Argues with other family members about how to best provide care (20%)
- ▶ Can't spend enough time with children as would like (19%)

Multiple Sclerosis Caregivers Report 2012

from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research

Marriage

- ▶ Females more likely abandoned/divorced by husband after diagnosis. (Glantz, 2009)
- ▶ But...motivating factor for CGs – marriage vows and commitment to marriage important. (Mutch, 2010)



Factors in Relationship Strength

Interviews w/ 8 (MS/CG) Couples (Starks, et al., 2009)

In-Sync	Out-of-Sync
MS Type: Relapsing/Remitting	MS Type: Progressive
Gradual onset of symptoms/impairments	Acute onset of symptoms/impairments
Slower progression of disease w/periods of remission	Faster progression of disease w/few (if any) remissions
Life roles/changes mostly 'on time'	Considerable disruptions to life roles & timing, including premature retirement
Share similar attitudes/approaches /strategies to problem-solving; frequently work as a team	Have different attitudes/approaches/ strategies to problem-solving; not always working as a team
Similar work/personality styles	Opposite work/personality styles previously complementary but in the context of increased demands become a source of conflict
	Adolescent children in the home

MSCoE Research

Veterans with MS:

- Higher proportion of males w/MS.
- More disabled & higher % of progressive forms of MS.
- Male Veterans w/MS who are married/living with someone, and/or RRMS reported high level of support from CG. Higher than married women Veterans w/MS.
- Women w/MS w/higher income felt greater social support. (Williams, Turner, et al., 2004)
- The greater global perceived social support from Veteran & greater affectionate support from CG, the less depression in Veteran. (Bambara, Turner, Williams & Haselkorn, 2010)



Caregivers of Veterans w/MS

- “Supportive qualities” of CG significant for better DMT adherence. (Siegel, Turner & Haselkorn, 2008).
 - ✓ Important not only for CGs, but also for clinicians to implement into practice.

I don't have time to do a CG assessment.

It will interfere with my natural flow in clinical practice and get in the way of building trust with the Caregiver and client with MS.

Yes or No?



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Myth: I don't have time to do a CG assessment...it will interrupt my flow and interfere with client trust.

Reality

- ☑ CG assessments are tools to guide the conversation and clinical practice.
- ☑ Assessments can pick up on issues concerning CG that may not be obvious.
- ☑ Assessments can be shortened, efficient and adapted for clinical use.
- ☑ Most importantly, the caregiver will feel listened to and acknowledged.

I won't have the answers or resources
to deal with Caregiver issues.

Yes or No?



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Myth: I won't have the answers or resources to deal with Caregiver issues

Reality:

- ☑ Avoiding or excluding caregiver issues can lead to bigger problems with care.
- ☑ It is possible to work creatively with caregivers to tailor the use of limited resources.
- ☑ There are more resources than ever on the internet and accessible to caregivers.

Caregiver Assessments

- ❖ Sullivan Lit. review (2008) of 9 CG assessments.
 - Recommends CSI: short, easy, objective.
 - ✓ Zarit Burden Scale (Zarit, 1980) (public domain)
 - ✓ Caregiver Strain Index (CSI) (Robinson, 1983)
 - ✓ Caregiving Tasks in MS Scale (CTiMSS) (Pakenham, 2007)
 - ✓ Caregiver Reaction Assessment Scale (CRA) (Given et al., 1992)
 - w/SF-36 (Forbes, 2007) – 257 MS CGs survey
 - ✓ CAREQOL-MS: Caregiver quality of life (Benito-Leon, 2011)
 - Specific to MS CGs. Will use examples of it later in Lisa's Case Studies presentation. Lisa found useful for her caregiver clients.

Caregiver Assessments

1. How many of you use these assessment tools? Yes/no



Comprehensive Caregiver Assessments

- Context
- CG's perception of health and functional status of care recipient
- CG's values and preferences
- Well-being of the CG
- Consequences of Caregiving (perceived challenges & benefits)
- Skills/abilities/knowledge to provide care recipient with needed care
- Potential resources that caregiver could choose to use

Family Caregiver Alliance (2006). Caregiver Assessment Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference (Vol. 1) San Francisco, CA.

Critiques on Assessment Tools

- ▶ Focus on burden rather than strengths.
- ▶ Caregiver assessments often do not recognize multiple caregivers.
- ▶ Many assessment tools not designed within a multicultural framework.
- ▶ Length of questionnaires/time takes to give questionnaire.
- ▶ There is not one that focuses on everything.
- ▶ Specific questions direct to specific issue.
- ▶ Others???

Models of MS CG Support

“Powerful Tools for Caregivers”

- Award winning national program supported by community-based organizations.
- 6 week educational series designed to provide family caregivers with tools needed to take care of themselves while caring for a loved one.
- Self management, skill building in stress management, communication, decision making.
- Based on study & program by Kate Lorig, et al. Stanford U.
- www.powerfultoolsforcaregivers.org



Models of MS CG Support

▶ VA MS Centers of Excellence

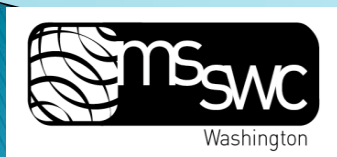
- Monthly National Caregiver Education & Support Conference Calls
- MSCOE Website: www.va.gov/ms
- Books, DVDs, Pamphlets
- SW led Caregiver Support & Education Series (From pilot model of MSCOE)

▶ VHA Caregiver program

- Supported by VHA
- Annual Conference for Caregivers (20 years!)

▶ VHA Care Coordination Home Telehealth Program (CCHT):

- Caregivers interviewed using Zarit Burden Scale of Caregivers.



FROM CAREGIVING TO CAREGIVER

Allison Fine, MSW
Counseling for Inner Balance
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Positive Impact on Caregiver

- Strengthened relationships
- Unique understanding of MS
- Sense of giving back
- Satisfaction in providing good care
- Self-pride



Washington

Negative Impact On Caregiver

- Physical and emotional stress
- Isolation
- Challenging care recipient
- Role reversals/changes
- Burden/fatigue
- Burnout



Washington

The Juggling Act



http://georgiawomenvote.blogspot.com/2007_11_01_archive.html

Role Reversal

- New responsibilities
- Unfamiliar tasks and routines
- Caregiver ---> Intimate Partner
- Who am I?



Emotional Health of the Caregiver

- Grief and Loss
- Depression
- Anxiety
- Environmental Stressors/Pre-existing conditions

***Alone or combined, can lead to caregiver fatigue or burnout



Washington

Grief and Loss

Emotional

- Shock/Disbelief
- Sadness/Depression
- Loneliness
- Guilt
- Bargaining
- Anger/Frustration
- Fear/Anxiety

Physical

- Weight Gain/Loss
- Fatigue/Insomnia
- Nausea
- Aches/Pains
- Lowered Immunity
- Difficulty Concentrating



Washington

Grief, Loss, and the Caregiver

- Loss of control
- Loss of who the person with MS used to be
- Loss of what the caregiver thought their life/future would be like
- Loss of sense of self
- Empathetic loss for the losses the person with MS experiences



Washington

Depression

Emotional

- Sadness
- Loneliness
- Frustration
- Anger
- Self-Loathing
- Self-Deprecation
- Suicidal Thoughts or Actions

Physical

- Weight Loss / Gain
- Fatigue / Insomnia
- Difficulty Concentrating or Making Decisions
- Loss of Interest in Daily Activities
- Unexplained Aches and Pains



Washington

Depression and the Caregiver

- Irritability toward person w/MS, family, or other medical providers or caregivers
- Caregiver says, “I don't know how much longer I can do this.”
- Caregiver says, “I'm tired of _____”
- Caregiver becomes tearful
- Caregiver feels hopeless – no change



Washington

Anxiety

Emotional

- Fear/Apprehension
- Feeling Tense or Jumpy
- Irritability
- Anticipating the Worst
- Watching for Signs of Danger

Physical

- Pounding/Racing Heart
- Sweating
- Nausea
- Dizziness
- Headaches
- Fatigue/Insomnia



Washington

Anxiety and the Caregiver

- Will my responsibilities as caregiver continue to increase as my care partner becomes more sick?
- Who will take care of my care partner if I'm not around?
- Will my role as caregiver ever end?
- Can anyone provide as good of care as I do for my care partner?



Washington

Stressors/Pre-Existing Conditions

- Relationship Trouble/Separation/Divorce
- Finances
- Job Stress/Unemployment
- Additional Medical or Emotional Diagnoses
- Safety or Security Concerns



Washington

Red Flags of Caregiver Burnout

- ▶ Culmination of intense feelings of loss, depression, anxiety, and/or stress
- ▶ Withdrawal from family, friends, and other loved ones
- ▶ Lack of self-care
- ▶ Fatigue
- ▶ Unreasonable demands or expectations for self and/or individual they are providing care
- ▶ Feelings of wanting to hurt self or person for whom they are caring



Washington

Caregiver Burnout

Total Exhaustion

- Physically and emotionally exhausted
- Inability to cope with any additional circumstances
- Inability to continue providing care

Depersonalization

- Loss of passion for caring for care recipient

Loss of Confidence

- Questioning whether they are the best person to provide care



Washington

Manifestation of Burnout

- Patients report feeling undercared for
- Lack of communication between caregiver and care recipient, family, friends, medical professionals
- Caregivers step out of care role
- Self expectations are unachievable
- Caregiver resents care partner
- Deterioration of relationship



Resources

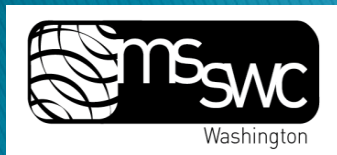
1. Caregiving and MS. *MS in Focus*, Issue 9, 2007.
2. www.apa.org/pi/about/publications/caregivers/faq/positive-aspects.aspx
3. DSM-IV
4. Elizabeth Kubler-Ross



Washington

SOCIAL WORK INTERVENTIONS

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Clinical Social Worker
MultiCare Neuroscience: MS Center
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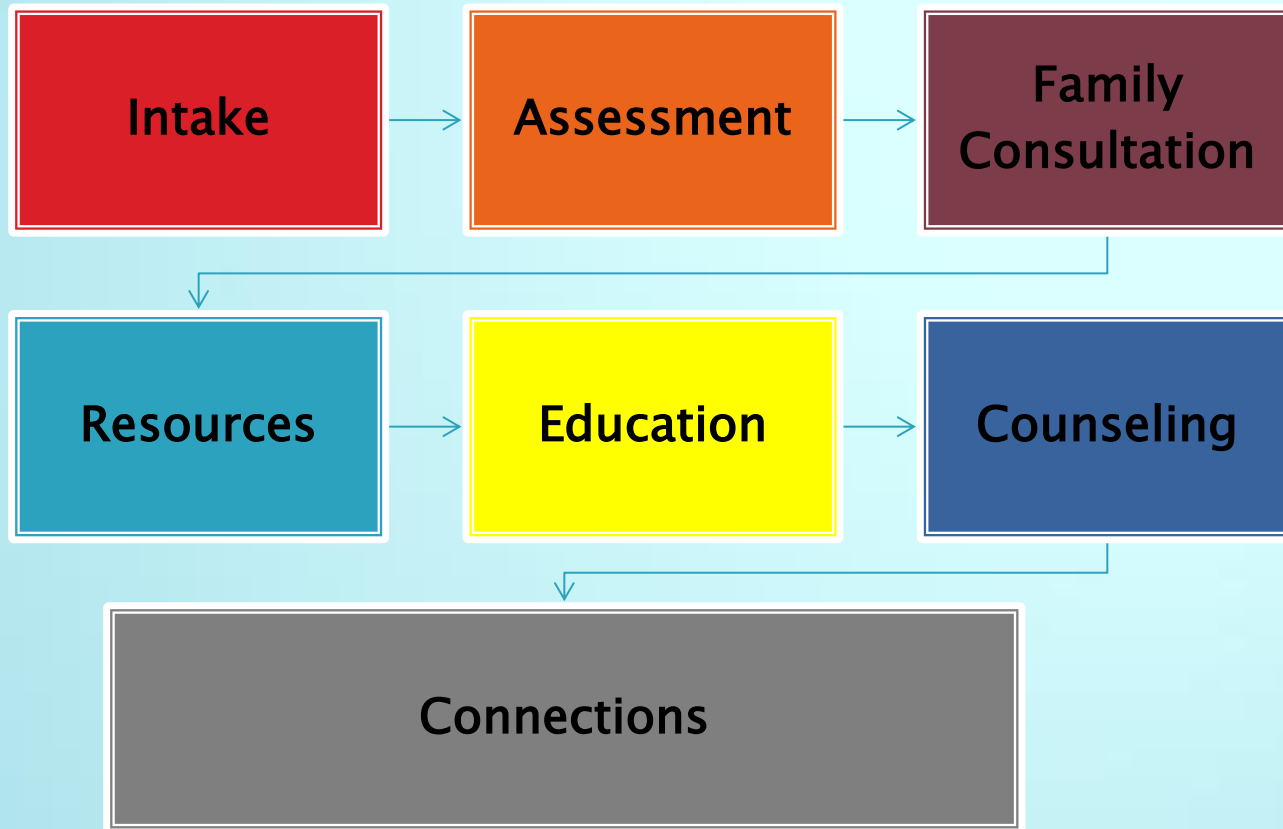
“Always bear in mind that our focus is on empowering family members to help themselves rather than managing their problems for them.”

~ Family Member and Caregiver Alliance co-Founder Suzanne Harris

Universal Themes Guiding the Interventions

- ▶ Family caregiver is the client
- ▶ Expressed needs
- ▶ Anticipate barriers
- ▶ Goal focused intervention
- ▶ Along the continuum of care
- ▶ Sustainability

Building Blocks



Unpacking the Blocks

- ▶ Intake
 - Identify needs
 - Validation
 - Community resources
- ▶ Assessment
 - Measure caregiver burden and stress
 - Biopsychosocial
- ▶ Family Consult
 - Create plan of care
 - Identify resources and planned interventions

Strength & Empowerment

- ▶ Resources
 - Respite
 - Various community supports
- ▶ Education
 - Formal and informal
 - Psycho and disease specific
- ▶ Counseling
 - Mitigate stress and burden
 - Provide general emotional support



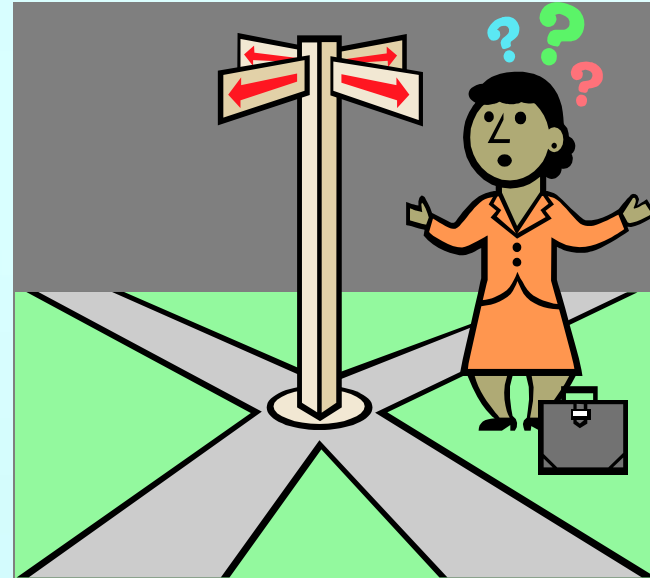
"This is not what I signed up for!"

- ▶ Psychoeducation
- ▶ Mindfulness
- ▶ Cognitive Behavioral Therapy
- ▶ Depression Management



"Now what?"

- ▶ Roles
 - Shift
 - Renegotiate
- ▶ Alleviate
 - Stress
 - Guilt
 - Fear
- ▶ Empowerment counseling
 - Strengths
 - Gratitude



"I feel like I am disappearing."

Rediscovering a Voice

- ▶ Advocacy
- ▶ Self-care
- ▶ Communication:
 - Skill building
 - Fair-fighting
 - Realistic expectations
 - Written agreements



Counseling

- ▶ Individual
- ▶ Couples
- ▶ Family as “Team”
 - with Children
 - with Extended
 - with Friends

- ▶ Groups
- ▶ Classes
- ▶ Books
- ▶ The Internet

A New Normal

- ▶ From Surviving to Thriving
 - Resilience
 - Gratitude
- ▶ On the Road Again
 - Increased connectedness
 - Updated map



Case Studies: MS Caregivers

Lisa Webb, MSW, LICSW
Virginia Mason Medical Center
Seattle, WA



Case Studies

- ▶ 3 Actual MS Client/Caregiver scenarios.
(names have been changed)
- ▶ Questions to think about.
- ▶ Application of CG Assessment
 - some CAREQOL-MS Questions.



Case Study #1

Phillip

- ✓ 33-yo single male, RRM-MS, onset 2003
- ✓ Symptoms mostly affect mobility, also has significant tremor
- ✓ Moved in with mother, home renovated to add downstairs apartment to accommodate Phillip
- ✓ Mother, primary caregiver, travels for work
- ✓ Phillip qualified for State program, COPES
- ✓ Phillip's care needs increased as MS progressed to total care, mother struggling to meet his needs
- ✓ Phillip once fell on his mother causing injury which prevented her ability to care for him for a week

Case Study #1

Phillip's Mom: Linda

- Linda needed knee surgery from arthritis so Phillip was placed in a skilled nursing facility.
- Even after surgery, she couldn't take care of him.
- Long-term plan is for him to remain at SNF.
- Linda still struggles emotionally and expressed desire to take Phillip back home.
- Linda still needs to be involved in Phillip's care as an advocate due to inadequate care he is receiving at the SNF.

Questions

- ▶ How can you support Linda with the decision to move Phillip to a nursing home?
- ▶ CAREQOL–MS Statements for Linda to Rate:
(1=not at all, 2=a little, 3=sometimes, 4=quite a lot, 5=a lot)
 - I'm scared about the progress and consequences of MS.
 - My own health has worsened over the course of this year.
 - Ever since the person whom I care for started suffering from MS, I devote less time to my own personal appearance and well being.

Case Study #2

Candy

- ✓ 26-yr female with Primary Progressive MS, onset age 13.
- ✓ Symptoms: mobility, also has tremor, cognitive dysfunction & depression.
- ✓ Moved in with father upon college graduation.
- ✓ Father became primary caregiver, very supportive overall.
- ✓ Candy's care needs increased over couple of years at home.
- ✓ Qualified for assistance from State program COPES.

Case Study #2

Candy's Dad: Frank

- Frank became a paid caregiver.
- There has been tension in relationship given Frank's role as caregiver (blending between father/caregiver responsibilities).
- Candy now wants to move out of the house and live independently.
- Frank admits to struggling with caregiver burnout but very worried about Candy moving out.



Questions

- ▶ What resources would be helpful to Candy and Frank?
- ▶ CAREQOL–MS Statements for Frank to Rate:
(1 =not at all, 2=a little, 3=sometimes, 4=quite a lot, 5=a lot)
 - I reflect about the suffering that limited mobility brings to the person with MS whom I care for.
 - The attitude of the person with MS whom I care for elicits mood changes in me.
 - Taking care of a person with MS has meant a change in my lifestyle.

Case Study #3

Esther

- ✓ 49 yo married female w/Secondary Progressive MS since age 27.
- ✓ Baseline hemiplegia requires moderate assistance.
- ✓ Symptoms primarily physical w/some cognitive decline.
- ✓ Married 20+ years. Husband is primary caregiver.
- ✓ Esther's care needs continue to increase to the point where husband questions his ability to continue providing care.
- ✓ Paid caregivers assist when husband travels for work.
- ✓ Esther and her husband exploring care options as her needs increase.
- ✓ Esther wants to remain at home.

Case Study #3

Esther's Husband: Ted

- Ted has an out-of-town lover who Esther is aware of and permitting as a way to save her marriage.
- Ted admits difficulty watching Esther's MS progression; their relationship is based on intellectual activities now more challenging to Esther.
- Esther in a transitional care facility for a month recovering from multiple medical issues and will discharge to her home.
- Ted is concerned about Esther's return home with fear:
 - "Does she have enough care at home?"
- Ted has his own health issues that need to be addressed.
- Esther has expressed she feels Ted is "checked out" at times.

Questions

- ▶ What can the team do to help Ted reconnect with Esther emotionally and intimately?
- ▶ CAREQOL–MS Statements for Ted to Rate:
(1 =not at all, 2=a little, 3=sometimes, 4=quite a lot, 5=a lot)
 - Multiple sclerosis has affected my relationship with my partner either regarding our sexual or emotional relationship.
 - I believe some psychological aid would help me provide better care for the person with MS.
 - I have been suffering from sleep disturbances since I learned that the person whom I care for suffers from MS.



Resources

Community Resources

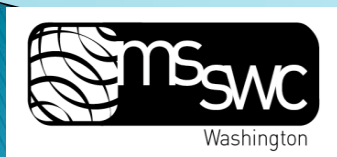
- ❖ The National Alliance for Caregiving: www.caregiving.org
- ❖ Powerful Tools for Caregivers: www.powerfultoolsforcaregivers.org
- ❖ Today's Caregiver Magazine: www.caregiver.com
- ❖ National Family Caregivers Association: www.nfcacares.org
- ❖ A caregiver managed website: www.caregiverscommunity.com

MS – Specific Resources:

- ❖ MS International Federation: www.msif.org/en/life_with_ms/family_friends_and_carers
- ❖ CMSC: www.mscares.org/cmcs/News/Web-Sights-Caregivers-Stress-2.html
www.mscares.org/cmcs/News/Web-Sights-MS-Caregivers.html
- ❖ National MS Society:
www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/index.aspx
www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/carepartners/index.aspx

VHA Resources

- ❖ VA Caregiver support line: (855) 260-3274
- ❖ VA Caregiver Support: www.caregiver.va.gov
- ❖ VA MS Centers of Excellence (MSCoE): www.va.gov/ms



Assessment Tools – References

- Zarit Burden Scale (Zarit, 1980) (public domain)
www.aafp.org/afp/20001215/2613.html
- Caregiver Strain Index (CSI) (Robinson, 1983)
www.npcrc.org/usr_doc/adhoc/caregiver/Caregiver%20Strain%20Index.pdf
- Caregiving Tasks in MS Scale (CTiMSS) (Pakenham, 2007)
 - Email Dr. Ken Pakenham: kenp@psy.uq.edu.au
- Caregiver Reaction Assessment Scale (CRA) (Given et al., 1992)
 - Email Dr. Barbara Given, Michigan State University. barb.given@hc.msu.edu
- CAREQOL–MS: Caregiver quality of life (Benito–Leon, 2011)
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